

MCHB/Director Webcast

Prevalence of the Autism Spectrum Disorders (ASDs)

April 28, 2010

DEIDRE WASHINGTON: Good afternoon, everyone. I am Deidre Washington and I'll be serving as the moderator for today's presentation. But before we get started, I would like to go over some logistics about the webcast.

Please note that the slides will appear in the central window and should advance automatically you may need to adjust the timing of the slide changes to match the audio by using the slide delay control at the top of the messaging window. Also, on the left side of the interface is the video window. You can adjust the volume of the audio using the volume control slider, which you can access by clicking on the loudspeaker icon.

Additionally, we encourage you to ask the speaker questions at any time during the presentation. Simply type your question in the white message window on the right of the interface, select question for speaker from the dropdown menu, and hit send. Also don't forget to include your state or organization in your message so that we know where you are participating from. The questions will be relayed to the speakers periodically throughout the broadcast. However, Dr. Rice will answer all questions at the end.

Those of you who selected accessibility features when you registered will see text captioning underneath the video window.

And finally, at the end of the broadcast, the interface will close automatically and you will have the opportunity to fill out an online evaluation. Please just take a couple minutes to do so at the end and fill out your evaluation. That was the logistic part. That's the end of that.

As many of you may already know, April is autism awareness month and here at the health resources and services administration Maternal and Child Health we have several programs through our combating autism initiative that focus on research, training of providers and improving the system of care in states for children and families affected by autism spectrum disorder and other disabilities. With those investment in mind we have implemented several additional activities during April in recognition of Autism Awareness Month. This webcast is our last activity for the month and is a collaborative activity with the Centers for Disease Control and Prevention who we work very closely with on several other autism-focused activities. Today's presentation will focus on the "Prevalence of Autism Spectrum Disorders - Data from CDC's Autism and Developmental Disabilities Monitoring Network"

It is a pleasure to have with us today our presenter, Dr. Catherine Rice. Dr. Rice is a behavioral scientist with a developmental disabilities branch at the National Center on Birth Defects and Developmental Disabilities at CDC. She has worked with people with

an autism spectrum disorder through teaching, diagnostic assessment, program planning, consultation, training and research for over 18 years. Dr. Rice currently works at CDC and her work includes partnering -- working with partners to track the rate and describe the population of children with ASD in multiple areas of the United States through the autism developmental disability monitoring network. In addition to work on the prevalence of autism spectrum disorder in the United States and internationally she provides input on CDC learn to find early campaign and third as a CDC liaison to the interagency autism coordinating committee. It is a pleasure to have Dr. Rice with us. Dr. Rice?

CATHERINE RICE: Thank you very much, lieutenant Washington, for that introduction. I appreciate the invitation by HRSA to present today. If we could go to the next slide I would appreciate it. So the title is "Prevalence of Autism Spectrum Disorders - Data from CDC's Autism and Developmental Disabilities Monitoring Network" I'm going to be talking a little bit about CDC activities in terms of monitoring the prevalence of autism.

If we can go to the next slide that shows two different figures at the bottom. We understand that many people have been concerned about how many children are affected with autism and I'm saying children because that's where the concern initially was arising particularly during the mid 1990s. There seemed to be more children coming to service systems under the eligibility of autism and the two figures down at the bottom of your slide are some examples of data that show us more children coming

into service systems on the left are the number of children coming into the California Department of developmental disability services and on the right children getting special education services under the eligibility which is different from a diagnosis but a way a child becomes eligible to receive special education services in the public school system. So through this experience, it was very clear that more children were coming into these systems being diagnosed with autism and receiving services under a specific classification of autism or one of the related disorders such as Asperger's or PDD and OS. A challenge we have in making sense of that time period is that there were a lot of changes in terms of the classification of autism. In 1994, the criteria for the pervasive developmental disorders of which autism is one, were changed to include as Berger's. New regulations were put in that listed autism as a special educational eligibility for the first time in the early 1990s. Those students with autism have been around for many years. There wasn't a specific classification to receive services for that condition. So that complicates our ability to go back and say exactly what is happening here. So I want to talk a little bit about some of the CDC's efforts to do that. How do we know how many children have an autism spectrum disorder? It seems very obviously certainly, if you know much or individuals or are an individual with an autism spectrum disorder you know there are challenges that is the reason why the ASDs are considered developmental disability. Challenges in communicating, in interacting, in learning and in interacting with the environment in the ways that other people do. But there are a lot of reasons why a child or an individual across the life span may have a diagnosis of an autism spectrum disorder. When I say that, I mean the specific pervasive developmental disorders, autism. Not otherwise specified or

atypical autism or as Asperger's. They're the autism spectrum disorders and we have little population base data on not just the classification of autism, but who actually has the constellation of features that make up an autism spectrum disorder. So we know more people are being identified but a challenge we have is that autism spectrum disorders are behaviorally defined. We don't have a clear-cut biologic examination or test that helps us determine yes or no autism is present. In many situations for an individual it can be clear that this person's profile, their early developmental history, the challenges they're having really come together to be an autism spectrum disorder but it is challenging for some individuals who may be more mildly affected to determine if this a feature of ASD, an overlap with a learning challenge or ADHD. We need a systematic way to screen that population to say not only how is the community identifying individuals with autism but what the are symptoms and features like that make up these set of conditions. There are several ways you can do that population-based screening. One is through a direct screening where you actually go and you either ask questions of a caregiver or you do some assessments directly with the child and follow that up with a diagnostic assessment. Now, a challenge we have particularly in the U.S. is having access to a very large population like that and having very good participation is a challenge. It takes a lot of effort and commitment and very similar to what is going on with the census right now of having people, all the education that goes behind trying to get people to fill out the simple ten questions, that's a challenge to get very high participation rates. So when you're talking about a series of assessments that are going to take hours of time, it is a challenge to be able to accomplish that. There are some other countries that have more routine screening as

part of ongoing pediatric care that have been able to do some of these screening studies but we're more limited at this point in the U.S. CDC does have some projects where we're working on that but what we've been using is another method, which is looking at records. I'll describe that in just a minute. Another way of looking at the population is by reports. Just asking people have you or your child -- has your child ever been diagnosed with one of the autism spectrum conditions? That's the process that has been used in some of our national surveys and I'll talk about that in just a minute. The challenge with that is that there is an issue with validation. You are just asking for people's experience and you aren't then having direct contact being able to look at the child's developmental profile to really see what makes up those symptoms? What is behind this report? It is can very useful information but there are limitations as well. Another method that I mentioned was the records-based method. That's the method I'll be talking about. There are some pros and cons as there are with any method but one of the reasons we used records-based screening because in the United States we have a variety of systems that evaluate children. Not every child may be evaluated by the same type of provider at the same time but we have multiple systems. We have the education system that if there is a concern related to a child's educational achievement it could be related to a behavioral development charges we have a system of free evaluations that look at that in the public school system. In addition, we have a variety of private and public healthcare providers that provide secondary evaluations whether it's psychologists, psychiatrists, speech therapists as some examples. So what we do is we go to a certain area and we look at the records

of children putting that information together to help us understand the features of autism and I'll describe that a little bit more in a minute.

Next slide, please. So stepping back a little bit, what we know about the prevalence of autism has been -- it's been changing. We've gotten a better understanding lately but we certainly have a lot of work to do. The first epidemiologic study of autism which tries to look across the whole population was done in the 1960s. So even though autism was first identified in the 1940s, the first EPI study was done in the 60s. From the 60s to the 80s there was relative consistency looking at children who had autism, severe language impairments, a wide variety of unusual and challenging behaviors. And those estimates were 4 to 5 for 10,000 children or 1 in 2,000 children with autism. Since 1980, which was the first time we had diagnostic criteria specific to autism in the diagnostic and statistical manual as the APA we've seen a broadening of autism to include conditions like atypical autism and so prior to this inclusion of the criteria in 1980 autism was considered a form of schizophrenia and we had a different mindset and looking at the condition as a developmental disability that may have multiple forms. Those criteria continue to be changed and tweaked somewhat from 1987, 1994 when there were changes in the criteria. Taking the more modern criteria into account that looks more at the spectrum, more recent estimates have been an average of 6 to 7 per 1,000 children. So certainly quite an increase of over 10 fold. More recent studies have even been higher and I want to talk about that next and we can go to the next slide.

So last year in 2009 there were two papers that came out about the prevalence of autism spectrum disorders in the U.S. One was CDC colleagues collaborated with a HRSA initiated paper on the survey of children's health authored by Michael KOGEN and colleagues and published in "pediatrics." Looking at parent reported. I'm not going to talk a great deal about that. Hopefully people have heard a lot about that study. I'm going to focus a little bit more on the second study that was published last year which is by the autism and developmental disabilities monitoring network. Looking at the autism spectrum disorders in 2006 in multiple areas of the U.S. The ADDM network is a collaborative effort among multiple sites around the U.S. To characterize the population of children with ASD, describe variation by subgroups and over time, certainly to determine prevalence in those groups and to evaluate methodological factors that -- and form hypotheses on potential risk factors.

On the next slide you'll see maps of the U.S. The ADDM network started data collection in 2001 and since that time we've had a couple of phases of sites funded. The current report includes 11 of the ADDM network sites.

Next slide, please. So next I want to talk a little bit about the method. As I mentioned we're using a records-based screening so what we do is we identify an area that has at least a minimum of 20,000 individuals of the target age that we're looking at. And we focus on age 8 because we're trying to identify peak prevalence. We did earlier studies at CDC that showed if you looked at autism across a variety of ages in early childhood, and early school age, we found that the highest rate of children was identified at age 8

and in the case of autism, we think some of that has to do, children are identified and have evaluations at a school or healthcare provider early on in life but there are some children that may not come to attention until later. Maybe they come to attention because they are in elementary school and having challenges and getting along with the school environment or learning challenges or communication or social challenges which triggers an evaluation or triggers concerns. So -- we see that by age 8 children have had an opportunity to have their developmental concerns made aware and followed through on some type of evaluation. So what we do is we look for multiple sources of information and not only looking for an actual diagnosis of autism, or an autism spectrum disorders but behaviors associated with autism as well. So we go to -- in many sites we're able to go to education sources and look for kids who have been evaluated for special education and then we're determine to have an autism eligibility or were determined to have other eligibility. Other health impairment or other disabilities. We go to different clinical resources to say not only which children that are age 8 in a particular year that we're looking at in this particular area, either have a diagnosis or a suspicion or test related to autism but are there any behaviors that could be related to autism? If we see a documentation of one of the social behaviors related to autism, say challenge in terms of wanting to have friends but not understanding the social rules. Or having poor eye contact. That would be enough to trigger that particular child for evaluation based on their records where we compile information across multiple sources, put this together as a detailed description of testing across this child's life up through the age of 8 and then we have a clinician who goes through using a set of criteria that we've standardized based on the DSM-IV criteria. We put

that together. We then confirmed that the developmental history and the symptoms related to one of the ASDs are present and determine that for counting purposes and population description that that child meets those criteria.

Next slide, please. So that's the basic method that the ADDM network uses. So when you hear according to CDC how many children have an ASD that's based on the ADDM network reporting using this method. The first report from them came out in February of 2007 and for multiple sites around the country there was between 1 in 100 and 1 in 300 children identified with an ASD with an average of 1 in 150 children. In the report that came out this past December in 2009, we found slightly different estimates and I'll describe those in just a minute.

Next slide, please. So for the sites that we looked at in the most recent report, we had 11 sites included, which covered a variety of areas depending on the site. It could have been anywhere from one county up to half of a state. Or the majority of a state. On this slide you can see the site, the area and then the population of 8-year-olds in the area that's included. Overall the population of screen included over 300,000 8-year-old children, a large coverage of the population.

Next slide. Next this slide has got a lot of numbers on it but just to sort of orient you, while we are doing a record review, we're doing a retrospective record review. They have to exist and be available to look at and put together. So we're often going back in time and also what we're trying to do is cover a crucial time period as I mentioned

earlier the concerns about increases in autism really started throughout the 1990s. So what we're trying to do is go back and build a dataset that looks at how autism was distributing among children in these areas using the same methods over time to cover children who are born throughout the 90s forward. The first to volunteer were children who were age 8 years of age in the year 2000 but born in 1992. If you look on the far right-hand side you'll see the average prevalence among these sites with 6.7 per thousand. Very similar for children born in 1994. 6.6 per thousand. That's about 1 in 150 children as an average. As we go to the next years, 2004 children born in 1996 we see a jump to about 8 per 1,000 children and then in 2006 born in 1998, we see an average of 9.0 per thousand children.

As we go to the next slide we'll see that this ranged from about 1 in 80 to 1 in 240 children with an average of 1 in 110 children with an autism spectrum disorder. That's about 1% of 8-year-old children with an ASD. Very similar to what was found in the report I mentioned by Michael Kogen and colleagues using the National Survey of Children's Health. Here we're able to look at the variation among the sites included. Although you see with the blue dots as the point prevalence of how many children were thousand on average for that site, but then the confidence intervals indicate what is the range plus and minus given some degree of error there. So you see that for most sites there is an overlap where there is a relative consistency and given the fact that autism is a behaviorally defined condition it's actually somewhat of a surprising thing to have such consistency across the sites but we can find some sites that had a lower prevalence and some with a slightly higher prevalence of autism. We better

understand the sites that had the lower prevalence of autism because we try to quantify even though each site is trying to implement the exact same protocol, there are some variations that we can't control. For instance, not every site was able to access and evaluate information and educational records. Of our sites with lowest prevalence Florida and Alabama were two of the sites not able to look at that power. Has a minimal estimate of how many children may have autism in those communities.

Next slide, please. Some of the other things that we found was very similar to what has been reported important many, many years, even back when prevalence estimates were based primarily on the core of autism versus the spectrum is an average of four to five boys for every girl. So more specifically .45 boys to the every girl. So for boys that's about 1 in 70 boys and for girls about 1 in 315 girls that are born in a population will eventually have the symptom and profile associated with an autism spectrum disorder. These findings are very concerning in that although it's a very similar ratio in boys to girls, this is a lot more boys and girls than have been seen in the past. But very consistent with the survey data and updated or recent prevalence coming out of other countries. So we also look by race and ethnicity. We found that white children were more likely to have an identified ASD than black children or Hispanic children. But we did see over time when we're looking at changes across surveillance years I'll show you in just a little bit that we're seeing higher increases among in particular Hispanic children giving us an indication that this difference in terms of prevalence probably has more to do with identification and who gets evaluated and how that information is documented in records than it does about a true racial or ethnic difference between the

prevalence of an autism spectrum disorder. Being able to look at these data over time in the same site will help us sort of tease out some of the identification factors versus things we can't explain that may be more an indicator of risk.

Next slide, please. So some other things I'm not going to go through all the data we collect but just a few of the basic highlights. Because we have this history of information about how children have been evaluated for developmental concerns we're able to see when was the first concern about the child that was documented? And the majority of children 70 to 95% of children that we identified with an ASD at age 8 had a documented developmental concern before the age of 2 years. So this indicates that relatively early in life that either a parent or a caregiver or a professional provider was concerned enough about how the child's development was proceeding or not proceeding to bring them to a provider to talk about their developmental issues and to write that down in a record. So that's actually a pretty positive finding that we are seeing that kids that later have very clear developmental issues related to autism, that flags are being raised early on in life. Some of those flags are indicated by the reports of developmental regression, 13 to 30% of children are reported to have had a skill and then lost it. Most often language. And so this in reviewing records we're not necessarily able to validate the presence of regression or not but we know that one was reported. So despite these early concerns, we are finding a delay in terms of the actual diagnosis of an ASD. These are children that have the confirmed profile of an ASD from early on in life, people are concerned about them, but their first diagnosis of an ASD on average is about 4 1/2 years. Depending on the site it ranged from 3 1/2 to 5

years of age. Now, we do see that some of the things that indicate an earlier diagnosis are being a boy, having an intellectual disability, having regression. Those in particular are sort of indicators of being identified earlier on. So we know as a community in terms of our efforts to improve identification, we certainly need to be looking for the signs of autism across all children but we need to be in particular look-out for among girls, among children who may not have intellectual disability and also among -- we did find a difference that white children are more likely to have a diagnosis at all even though their age may not be earlier, they're more likely to have a diagnosis at all. So that we need to be very conscious in terms of evaluating concerns about autism among all children despite gender and race and ethnicity.

Next slide, please. Another thing we're able to look at is among children who we have - - we have sites that are able to use special education records, that the majority of the children there is a very high participation in public special education. Depending on the site there is some variability but overall very high that children identify with an ASD are receiving some form of special education. That could be anywhere from a very brief consult to full day special education services. But one thing we see a lot more variability on is how those children are being classified across the states. That the use of the autism el will guy built, although there are Federal guide -- guidelines for how that eligibility is utilized for programming states vary in how it's implementing and how common it's implemented. That really tells us that if you are trying to really understand what is happening among the population of people with an ASD, that looking at education data by itself may be very helpful for indicating services and who is identified

but it doesn't really give us the full picture in terms of how many children may really be out there that have the symptom profile of an ASD.

Next slide, please. The next thing I want to talk about is changes in ASD prevalence. We had ten sites where we were able to look over two time periods in this report from last December and this was children born in 1994 and 1998 who were 8 in 2002 and 2006.

Next slide. Among these children we found very consistent trends overall but variation by site. Overall there was a 57% increase in ASD prevalence among children. This included a 60% increase among boys, a 48% increase among girls but really -- I'll show you in just a minute there was some variation. So it was very consistent that boys were more likely to have autism from 2002 to 2006. Girls it really depended. Some Sites were more likely. Some didn't change and some went down slightly. Also we saw increases among some of the racial and ethnic categories we were able to look at. White children, black children, Hispanic children but we saw a greater increase overall among Hispanic children giving us an indication that better identification may be at play in that situation.

Next slide. So this is a picture of showing the prevalence of ASD in blue in the year 2002 to 2006. So the average across all of these sites is a 57% increase. But within the sites there was variation. So from 27% increase in Colorado to 90% in Arizona.

Next slide. Also the next slide shows absolute change among boys and girls. So basically the blue lines show us that although for boys on average there was a 60% increase, that really varied again by site. But was very consistent that all sites did show a significant increase. Among girls there was an increase in the majority of sites. It was significant in terms of statistical terms in four of the sites but this is still extremely important that we are seeing increases among girls but not as consistently as we are among the boys.

Next slide. Similar in terms of race and ethnicity where we see these overall trends of increases but the magnitude really varies by site.

Next slide. Another thing that we are able to look at is although we know looking at cognitive functioning using intellectual quotient scores is a crude and minimal estimate of the ability of people with autism it is a quantitative measures. We looked at children who had intellectual quotient scores and how they were representative of having cognitive impairment or termed mental retardation for developmental disability. Having a borderline IQ and close to intellectual disability but not quite meeting those cutoffs to those children who had intellectual quotient scores with an IQ over 85. One of the things that have been put forward is that the increase in autism prevalence is primarily related to an identification of higher-functioning children with autism. Meaning children often with average to above average intellectual ability. Although we did find greater increases among children in the borderline and average to above average IQ ranges, we also still found increases among children with cognitive impairment. Although it

doesn't map exactly, those kids may often be more similar to classic autism. Children that have intellectual disability may have more language challenges and more severe behavioral challenges. It doesn't always map directly. So although we are seeing that some of this increase is this disproportionate identification among higher-functioning children, it is across all levels of functioning. And another thing we're seeing is that for earlier estimates when we looked at just autism, it was typically found that about 3/4 or 75% of children also had intellectual impairment. Here we're finding in both the earlier 2002 and then in 2006 years a much lower level of cognitive impairment. 41% of children with cognitive impairment indicating that the majority of children are having borderline to average or above intellectual functioning. So overall this is a more mildly affected population in terms of co-occurring intellectual disability.

And this next slide just shows similar, again, the change showing that while we see these overall trends that vary somewhat by site of what is making up the trend. There is more specific data in terms of all the point estimates in the actual prevalence report in table 5 if you're interested in looking at that.

Next slide. Another thing we looked at was the sub type. So there are a lot of challenges in terms of sub types of autism and debates, including by the current DSM V committee because of distinguishing between sub types. But we did want to look at how are professionals in the community diagnosing individuals with an ASD by subtypes and although there is lots of points on this figure with the blue, red and yellow, overall what we did find is what you would expect kind of what I was

mentioning before is the theory that more high-functioning individuals with autism are being identified in the community and why we're seeing such a prevalence increase. We would expect to see changes in the distribution in terms of children diagnosed with ought advertise particular disorder verses other disorders which doesn't map directly but are often considered more mild forms of an ASD. We didn't really see a shift. In some sites we did, so, for instance, in -- let's take Wisconsin, for instance, on the right-hand side you'll see that the blue portion of the figure increases from 2002 to 2006 indicating in that site they were more likely to see diagnoses of other ASDs like Asperger's over time. In Pennsylvania they saw the increase of the use of ought -- autistic disorder. 47% in 2006 were diagnosed with autistic disorder ever. So threes increases in terms of no matter how we looked at it by subgroup we're seeing increases in identified ASD prevalence using the methodology we used here. The big question is why is this happening? In terms of surveillance, our primary goal is to document what is happening to be able to describe the population. Hopefully this will inform policy but then we want to start to say well what can we measure and understand about how we were looking at this set of conditions, how it was affecting children, what information we had to determine how this was affecting children? And how does that relate to our prevalence estimates? So some of the things that we can measure help us look at what may be identification issues that contribute to some of the increases. So some of the things we did see was that we had more evaluation records. This somewhat speaks to community awareness and that children are getting evaluated more, the actual quality of the documentation, you know, ten years ago it was rare to see a description of peer social behaviors and we're seeing that a whole lot

more as we go in time. And that helps us be better able to determine hey, this particular criteria is present for this child and is part of this profile related to autism. We could also see that some sites were able to locate more records, had a more stable population, there was a decrease in the age of diagnosis, which would give the child more time to accumulate information. There was also better identification of Hispanic children and children without cognitive impairment. However, putting all these things together doesn't explain the overall 57% increase and one of the things that we've learned is our effort to say increases in identified ASD prevalence are not all awareness and identification. It is not all that we have a changing underlying risk population. It is very hard to prove or disprove that but what we're left with, what can we quantify and what is left unexplained? So what we know there is not a single explanation. We aren't going to find the one explanation that tells us but we'll have to look more -- in more complex ways at both the identification and the potential risk factors. So we definitely know there are multiple factors at play. There could be additional ascertainment or identification issues but a true risk -- increase in risk is certainly possible. So what we're doing next is try to go deeper into the data. In places where maybe we can do some analysis to help us understand risk. Can we do those analyses? People have talked about, for instance, changes in parental age in the population as being related to increases in autism. While we have found there is an increased risk of having a child with autism for both older mothers and fathers, the change in people having children at later ages has not been so great in the population to account for a huge proportion of this increase. So that may be a factor that helps explain a little bit of it but again not all. So we have to go forward and look at all the

multiple hypotheses out there and see how we can put them together for a more complex model.

Next slide. So what are some of the strengths of the methodology we use? A major strength is the collaboration in the multiple sites. We have multiple sites using a similar methodology working with quality control for consistency in a large population base. We have confirmation of the documented symptoms using the DSM criteria. Multiple sources of information and quality control. Some other sites will looking at other disabilities at the same time. Also now we're at the point we have a multiple year dataset to go back and to do further and more in-depth analyses.

Some of the challenges we faced on the next slide include maintaining the network of sites over time. The resources and the competitive process as the grant cycle is over. ReCompleting, wanting to be fair and have an open process, however, not wanting to lose the resource that has been built by a site that has been able to establish this process. Also some of the site-specific differences in methodology. While we try to control and standardize as much as we can, there are some things we can't, like access to certain records or quality of information. Another challenge we have is to be able to look at records. We have to do this retrospective and it is also a time inconvenience process. For instance, I mentioned that the most recent report covered a population of over 300,000 children. From that population there were over 50,000 records that needed to be reviewed and then go through the process of determining was there a suspicion of autism here. From there we identified 5,000

records that had to be reviewed by the commission group to identify approximately 2,800 children with an ASD. That's a complex and time intensive process but important for us to go beyond just saying who may be qualifying for services for autism but who may have the symptoms.

So on the next slide just to summarize, the overall findings is that the average prevalence of ASD is 1% of 8-year-old children or specifically 1 in 110 with a range in 1 in 80 to 1 in 140. 1 in 70 boys and 1 in 315 girls. It is similar to other recent studies. We saw a large prevalence increase over a short period of time and we know that factors explain some increase but can't completely account for the changes in ASD prevalence. So in addition I think a really important thing is although we saw some slight improvements in the age of diagnosis of ASD there are still significant delays so these numbers indicate that we have a lot of work to do in terms of making sure that children are identified and get into services as early as possible.

So on the next slide just in summary one of the things we do know for sure, although this may seem simple it's extremely important, that more children with ASD are identified and the impact on individuals, families and communities is significant and we hope -- next slide, please.

That these estimates can be used to help plan policy, to help get a better estimate of the service needs for people with ASD, and they also highlight the need for a coordinated, collaborative multi-wrong approach. We won't have one solution that

helps individuals and families with autism. We need to be working across agencies both public and private, looking at a variety of ways that we can better understand what puts people at risk, how we can improve early identification and access to intervention. How we can better understand how to intervene to reduce debilitating symptoms of ASD. How can we help people function to their potential that's meaningful to them in their life? And how do we improve sort of -- we have this range of services out there that, you know, we operate in many different systems but how do we help coordinate what is going on? We have a lot of challenges to face and having so many individuals affected, about 1% of children really highlights so many -- the fact that so many families and communities are struggling with these issues.

Next slide. In terms of CDC's action we're a public health agency so we're typically looking at the population level trying to provide the data and statistics to help us understand what's going on with the population, get a handle on at least some of the basics. We also have involved in research. We have a study to explore early development looking at some of the potential and risk factors. Potential risk and protective factors. Improve early identification of ASDs and contribute to the interagency autism coordinating committee, public and private coordination of research efforts related to ASD. So some of the things that the IECC in particular have highlighted. Although the ADDM network has really for the last several years become established to provide some of this basic data, the ICC has recommended we build on this infrastructure to keep estimating prevalence in the same population and evaluate more deeply what we can in terms of identification and risk factors. And also

hopefully through collaboration to expand the scope of surveillance. Increase the types of data collected. Look at other disorders, different age groups, help other communities struggling with these issues both nationally and internationally.

Next slide. So I would like to thank the principal investigators and project coordinators of the ADDM network. There is a large number of incredibly dedicated people involved who work very collaboratively across a variety of disciplines and I'm definitely thanking them for all they've put into this project and do for their local communities.

Next slide. And on the final slide is just the website where you can go and access the actual surveillance summary report that has the specific data as well as the CDC autism website that has additional data on autism and information and resources. So I appreciate your attention. It is always strange on a webinar not to be able to see faces and get feedback about how people are thinking or receiving the information but hopefully in the next few minutes we'll have opportunity to talk about questions and get more into some of the issues. So thank you again.

>> Thank you, Dr. Rice. That was a very informative presentation. It is always a pleasure to collaborate with some of our sister agencies and programs and projects. For the audience, please submit any questions that you have for the speaker using the messaging center on the lower right of the screen by selecting question for speaker if you have any. We do have a couple here currently. The first question is, can you discuss more about the changes for increase from 2002 to 2006 of ASD prevalence in

Colorado versus Arizona? What factors contributed to this distinct difference?

Apparently there was a 27% increase in Colorado and 90% in Arizona?

>> Uh-huh, right. Thank you for the question. The difference, those are the sites that had the lowest and highest prevalence. Colorado and Arizona. The increase from 2002 to 2006 was magnified in those sites. One of the things we know about Colorado was a challenge we had if you look in the publication of the population size, Colorado had the smallest population size and we basically in a statistical level didn't have quite a amount of power to look at changes in the same way. So although 27% increase is significant in terms of being a large increase, it wasn't in terms of statistical analysis. Why their prevalence is lower than Arizona there is no clear-cut explanation that we have. Some of the sites like, for instance, Alabama and Florida, as I mentioned, we have a very good indication that they're missing some of the information. We have a better understanding in that the large increase in Arizona, a lot of that has to do with the increase of identification of Hispanic children where they had a large change from 2002 to 2006 among that sub group which really contributed to their increase. But at this point it is unclear why the variation is so wide between those two particular sites.

>> Okay. Another question we have is the CDC have plans to expand the ADDM network?

>> Expanding the ADDM network. We just had the next program -- the announcement for new proposals came out earlier this year and they were submitted. The closing date

has passed and the peer review process has gone through but sites are not yet -- it hasn't been announced on number and specific sites. At this point with available funds we weren't able to expand the core ADDM sites but what we did is we're trying to expand to an earlier age so we are funding a small amount of sites to be able to look at autism prevalence among 4-year-old children. As I mentioned we look at 8 years of age because we know that's the peak prevalence but we'd love to be able, because it will help us get more timely information out, to look at a younger age. We are expanding to look at that younger age. In terms of adding additional sites it will just depend in terms of available funds in future years. We would certainly like to do that if those funds are available.

>> Another question we have here is how will the future changes to the DSM criteria impact the surveillance from the ADDM network?

>> The changes in the DSM criteria, as I mentioned, the DSM committee is currently meeting and on the DSM V.org website there should be criteria going through a vetting and evaluation process now. The plan is to have these new criteria in effect in 2013. We've been in contact with and we collaborate with several members of the DSM committee and have been able to do a very brief look at how the proposed criteria would affect our prevalence and we have concerns. One of the concerns is that the revised criteria -- in the current criteria that's one possible criteria but not required. And one of the things that we see in records is that is not something that's documented very well because often evaluators don't have peers in their office or have the

opportunity to evaluate peer interaction. So they look at other social criteria. So if we were to require the peer criteria we rarely see that documented as well as we would like to records. That would reduce our prevalence significantly. We are concerned about that and have relayed that information back. One of the advantages of the way we've collected the data is that because we have the behavioral descriptions we can code the data in different ways. We can use the criteria. And then be able to quantify the difference with the new cry tier ya. it is something we plan to integrate and evaluate and make sure we understand how it affects our prevalence. Thank you.

>> We do have one last question here. That is how is community professional defined? Who are the service providers categorized into this group?

>> Excellent detail question. Community professionals are people with advanced education who are in a professional position to evaluate the developmental status of children with developmental disabilities and there is a long list but I gave an example of a couple. But some of these are psychologists, developmental pediatricians, psychiatrists, psychologists, school psychologists, those are examples of who we're calling community professionals. Those professionally able to do developmental evaluation of children.

>> Dr. Rice, we'll take -- we have a last question. This is the last one, really. Okay. Here it is. Please describe exactly what you mean by active case filing. If all sites are conducting active case finding. Why would addition of educational records increase the

prevalence in areas with access to educational records? I assume educational records would be confirmed in medical sites where active surveillance is in place.

>> All right, good question. Active case funding in EPI terms means you aren't depending on more of a passive system of reporting. There are a lot of reportable conditions. Last year H1N1 and certain populations was reportable if it occurred you needed to report it to the health department. Some states have autism registries and it is a reportable condition. What we find in those passive systems where you wait to see, a professional sees this condition and reports it, you lose a lot of information and it's very often incomplete for conditions like autism. By active we're going out there and not just taking statements of diagnoses but looking for additional information. So the question of education records is really important because in those evaluations done for special education there is often a lot of very rich and important information on the child's developmental status. And we actually do see some overlaps. There are sites that don't have that information, for instance, Missouri is a site that typically you find those education records in other sources. There is a developmental disabilities public program that often has those records in there so we get that information in a different way. But other sites that's not the case. So, for instance, in Alabama and Florida we're not seeing that show up in the health records or in the developmental pediatricians and psychologist's office although we think that would be an active part of careful care coordination. We're just not seeing it. We're missing some of that key developmental information that is documented in that setting. Although we're actively seeking it, if you

can't get access to look for that information, you can't utilize it to add to your information.

>> Okay. Thank you so much, Dr. Rice. This has been a very informative presentation. Thank you very much for everyone listening in. Thank you for participating and also please don't forget to submit your evaluations immediately following this webcast which is about now. Okay? Thank you so much.

>> Thank you.